

TESTIMONY OF
MR. JACK STIBBS
CHAIRMAN OF THE BOARD
PULMONARY HYPERTENSION ASSOCIATION

ON BEHALF OF THE
PULMONARY HYPERTENSION ASSOCIATION
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REGARDING
FISCAL YEAR 2007 APPROPRIATIONS FOR CDC, NIH AND HRSA
PRESENTED TO THE
HOUSE LABOR-HHS-EDUCATION APPROPRIATIONS SUBCOMMITTEE

MARCH 29, 2006

SUMMARY OF FY 2007 RECOMMENDATIONS:

- **\$250,000 within the Centers for Disease Control and Prevention for a pulmonary hypertension awareness and education program.**
- **A 5% increase for the National Heart, Lung and Blood Institute and the establishment of “Specialized Centers of Clinically Orientated Research” on Pulmonary Hypertension at the Institute.**
- **\$25 million for the Health Resources and Services Administration’s “Gift of Life” Donation Initiative.**

Mr. Chairman, thank you for the opportunity to submit testimony on behalf of the Pulmonary Hypertension Association.

I am honored today to represent the hundreds of thousands of Americans who are fighting a courageous battle against this devastating disease. Pulmonary hypertension is a serious and often fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail.

PH can occur without a known cause or be secondary to other conditions such as; collagen vascular diseases (i.e., scleroderma and lupus), blood clots, HIV, sickle cell, and liver disease. PH does not discriminate based on race, gender or age. Patients develop symptoms that include shortness of breath, fatigue, chest pain, dizziness, and fainting. Unfortunately, these symptoms are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progress to a late stage, making it impossible to receive a necessary heart or lung transplant.

While new treatments are available, unfortunately, PH is frequently misdiagnosed and often progresses to late stages by the time it is detected. Although PH is chronic and incurable with a poor survival rate, the new treatments becoming available are providing a significantly improved quality of life for patients. Recent data indicates that the length of survival is continuing to improve, with some patients able to manage the disorder for 20 years or longer.

Fifteen years ago, when three patients who were searching to end their own isolation founded the Pulmonary Hypertension Association, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was unacceptable, and formally established PHA, which is headquartered in Silver Spring, Maryland.

Today, PHA includes:

- Over 6,000 patients, family members, and medical professionals.
- An international network of over 120 support groups.
- An active and growing patient telephone helpline.
- A new and fast-growing research fund. (A cooperative agreement has been signed with the National Heart, Lung, and Blood Institute to jointly create and fund five, five-year, mentored clinical research grants and PHA has awarded eleven Young Researcher Grants.)
- Numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension – published quarterly and distributed to all cardiologists, pulmonologists and rheumatologists in the U.S.

Mr. Chairman, I am honored today to appear before the subcommittee with my daughter Emily. At the age of 5, my wife and I noticed that Emily could not keep up with the other kids in the neighborhood. She seemed to lack the energy and strength to run and play. This condition seemed to worsen to the point to where she would have to stop and rest after coming down the steps in the morning. We noticed that when she was sitting on the bottom step in the morning, her lips appeared to have a bluish color.

After pressing for an answer to these problems for several months, Emily was finally diagnosed with pulmonary hypertension and the doctors gave a probable remaining lifespan of three years. That unforgettable day was 8 years ago and, as you can see, Emily is still here today. She is here because of continued advances in the treatment of pulmonary hypertension and by the grace of God. There is however, NO cure for pulmonary hypertension. Thanks to congressional action, Emily's chances of a full life have greatly increased. We need, however, additional support for research and related activities to continue to develop treatments that will extend the published NIH life expectancy beyond the 2.8 years after diagnosis.

FY07 APPROPRIATIONS RECOMMENDATIONS

A) NATIONAL HEART, LUNG AND BLOOD INSTITUTE

Mr. Chairman, PHA commends the National Heart, Lung and Blood Institute (NHLBI) for its strong support of PH research. According to leading researchers in the field, we are on the verge of significant breakthroughs in our understanding of the disease and the development of new and advanced treatments. Ten years ago, a diagnosis of PH was essentially a death sentence, with only one approved treatment for the disease. Thanks to advancements made through the public and private sector, patients today are living longer and better lives with a choice of five FDA approved therapies. Recognizing we have made tremendous progress, we are also mindful that we are a long way from where we want to be, and that is; 1) the management of pulmonary hypertension as a treatable chronic disease, and 2) A CURE..

Mr. Chairman, it is our understanding that NHLBI is poised to establish "Specialized Centers of Clinically Orientated Research" in pulmonary hypertension later this year. We are very excited about the promise these Centers hold for the future development of new treatments and we encourage the Subcommittee to support this worthy investment. In addition, we applaud NHLBI and the NIH Office of Rare Diseases for their plans to co-sponsor a two-day scientific conference on pulmonary hypertension this Fall. This important event will bring together leading PH researchers from the U.S. and abroad to discuss the state of the science in pulmonary hypertension and future research directions.

In order to facilitate the establishment of the Specialized Centers of Clinically Orientated Research and maintain promising research currently underway on PH, the Pulmonary Hypertension Association encourages the Subcommittee to provide NHLBI with a 5% increase in funding in FY07.

B) CENTERS FOR DISEASE CONTROL AND PREVENTION

PHA applauds the Subcommittee for its leadership over the years in encouraging the Centers for Disease Control and Prevention to initiate a Pulmonary Hypertension Education and Awareness Program. We know for a fact that Americans are dying due to a lack of awareness of PH, and a lack of understanding about the many new treatment options. This unfortunate reality is particularly true among minority and underserved populations. However Mr. Chairman, you don't have to rely solely on our word regarding the need for additional education and awareness activities. On November 11, 2005 the CDC released a long awaited Morbidity and Mortality Report on pulmonary hypertension. In that report, the CDC states;

- 1) *“More research is needed concerning the cause, prevention, and treatment of pulmonary hypertension. Public health initiatives should include increasing physician awareness that early detection is needed to initiate prompt, effective disease management. Additional epidemiologic initiatives also are needed to ascertain prevalence and incidence of various pulmonary hypertension disease entities.” (Page 1, MMWR Surveillance Summary – Vol. 54 No. SS-5)*
- 2) *“Prevention efforts, including broad based public health efforts to increase awareness of pulmonary hypertension and to foster appropriate diagnostic evaluation and timely treatment from health care providers, should be considered. The science base for the etiology, pathogenesis, and complications of pulmonary hypertension disease entities must be further investigated to improve prevention, treatment, and case management. Additional epidemiologic activities also are needed to ascertain the prevalence and incidence of various disease entities.” (Page 7, MMWR Surveillance Summary – Vol. 54 No. SS-5)*

Mr. Chairman, we are grateful to CDC for their recent support of a DVD highlighting the proper diagnosis of PH. However, despite repeated encouragement from the Subcommittee over the past five years, CDC has not taken any steps to establish an education and awareness program on PH. Therefore, we respectfully request that you provide \$250,000 in FY07 for the establishment of a PH awareness initiative through the Pulmonary Hypertension Association.

C) “GIFT OF LIFE” DONATION INITIATIVE AT HRSA

Mr. Chairman, PHA applauds the success of the Health Resources and Services Administration's "Gift of Life" Donation Initiative. This important program is working to increase organ donation rates across the country. Unfortunately, the only "treatment" option available to many late-stage PH patients is a lung or heart and lung transplantation. This grim reality is why PHA established "Bonnie's Gift Project."

"Bonnie's Gift" was started in memory of Bonnie Dukart, one of PHA's most active and respected leaders. Bonnie was a PH patient herself. She battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her death, Bonnie expressed

an interest in the development of a program within PHA related to transplant information and awareness. PHA will use "Bonnie's Gift" as a way to disseminate information about PH, transplantation and the importance of organ donation to our community and organ donation cards.

PHA has had a very successful partnership with HRSA's "Gift of Life" Donation Program in recent years. Collectively, we have worked to increase organ donation rates and raise awareness about the need for PH patients to "early list" on transplantation waiting lists. For FY07, PHA recommends an appropriation of \$25 million (an increase of \$2 million) for this important program.

Mr. Chairman, once again thank you for the opportunity to present the views of the Pulmonary Hypertension Association. We look forward to continuing to work with you and the Subcommittee to improve the lives of pulmonary hypertension patients. I would be pleased to answer any questions you may have.

JOHN H. "JACK" STIBBS, JR.

Mr. Stibbs is the managing shareholder of Stibbs & Co Attorneys in The Woodlands, Texas. Mr Stibbs practices corporate transactional law, covering a wide variety of both domestic and international corporate and energy law related matters.

Mr. Stibbs currently serves as the Chairman of the Board for the Pulmonary Hypertension Association (PHA). He became active with PHA when his daughter Emily was diagnosed with pulmonary hypertension.

Professional Memberships and Affiliations

State Bar of Texas; State Bar of Louisiana; Montgomery County Bar Association; Panel of Arbitrators of the American Arbitration Association; Certified Mediator; Admitted: U.S. District Court, Eastern District of Louisiana, U.S. District Court, Southern District of Texas, U.S. Court of Appeals, Fifth Circuit, U.S. Supreme Court .

Community and Civic Involvement

Independent Petroleum Association of America; Maritime Law Association; South Montgomery County Woodlands Chamber of Commerce (chairman, YEAR); the Woodlands Rotary Club (Director, YEAR); South Montgomery County YMCA (Director, YEAR); Economic Development Partnership of Montgomery County (Board Member, YEAR); Chairman of the Board, Pulmonary Hypertension Association, South Montgomery County Woodlands Chamber of Commerce (Vice President of Executive Board 2001); Southwest Bank of Texas (Advisory Board Member, YEAR).

Your Name: Jack Stibbs		
1. Are you testifying on behalf of a Federal, State, or Local Government entity?	Yes	No X
2. Are you testifying on behalf of an entity other than a Government entity?	Yes X	No
3. Please list any federal grants or contracts (including subgrants or subcontracts) which <u>you have received</u> since October 1, 2003:		
NONE		
4. Other than yourself, please list what entity or entities you are representing:		
PULMONARY HYPERTENSION ASSOCIATION		
5. If your answer to question number 2 is yes, please list any offices or elected positions held or briefly describe your representational capacity with the entities disclosed in question number 4:		
CHAIRMAN OF THE BOARD		
6. If your answer to question number 2 is yes, do any of the entities disclosed in question number 4 have parent organizations, subsidiaries, or partnerships to the entities for whom you are not representing?	Yes	No X
7. If the answer to question number 2 is yes, please list any federal grants or contracts (including subgrants or subcontracts) which were received by the entities listed under question 4 since October 1, 2003, which exceed 10% of the entities revenue in the year received, including the source and amount of each grant or contract to be listed:		
NONE		